



## **DEPARTMENT OF HEALTH AND HUMAN SERVICES**

### **Health Resources and Services Administration**

#### **Meeting of the Advisory Committee on Heritable Disorders in Newborns and Children**

**AGENCY:** Health Resources and Services Administration (HRSA), Department of Health and Human Services.

**ACTION:** Notice.

**SUMMARY:** This notice announces a public meeting of the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC or Committee), authorized under section 1111(g) of the Public Health Service Act, and the Federal Advisory Committee Act, on Thursday, May 12, 2022, and Friday, May 13, 2022. Information about the ACHDNC and the agenda for this meeting can be found on the ACHDNC website at <https://www.hrsa.gov/advisory-committees/heritable-disorders/index.html>.

**DATES:** Thursday, May 12, 2022, from 10:00 AM to 3:20 PM Eastern Time (ET) and Friday, May 13, 2022, from 10:00 AM to 12:40 PM ET.

**ADDRESSES:** This meeting will be held via webinar. While this meeting is open to the public, advance registration is required.

Please register online at <https://www.achdncmeetings.org/registration/> by the deadline of 12:00 PM ET on May 11, 2022. Instructions on how to access the meeting via webcast will be provided upon registration.

**FOR FURTHER INFORMATION CONTACT:** Alaina Harris, Maternal and Child Health Bureau, HRSA, 5600 Fishers Lane, Room 18W66, Rockville, Maryland 20857; 301-443-0721; or [ACHDNC@hrsa.gov](mailto:ACHDNC@hrsa.gov).

**SUPPLEMENTARY INFORMATION:** ACHDNC provides advice and recommendations to the Secretary of Health and Human Services (Secretary) on the development of newborn screening activities, technologies, policies, guidelines, and programs for effectively reducing

morbidity and mortality in newborns and children having, or at risk for, heritable disorders. ACHDNC reviews and reports regularly on newborn and childhood screening practices, recommends improvements in the national newborn and childhood screening programs, and fulfills requirements stated in the authorizing legislation. In addition, ACHDNC's recommendations regarding inclusion of additional conditions for screening on the Recommended Uniform Screening Panel (RUSP), following adoption by the Secretary, are evidence-informed preventive health services provided for in the comprehensive guidelines supported by HRSA pursuant to section 2713 of the Public Health Service Act (42 U.S.C. 300gg-13). Under this provision, non-grandfathered group health plans and health insurance issuers offering non-grandfathered group or individual health insurance are required to provide insurance coverage without cost-sharing (a co-payment, co-insurance, or deductible) for preventive services for plan years (i.e., policy years) beginning on or after the date that is one year from the Secretary's adoption of the condition for screening.

During the May 12-13, 2022, meeting, ACHDNC will hear from experts in the fields of public health, medicine, heritable disorders, rare disorders, and newborn screening. Agenda items include the following:

- 1) Final evidence-based review report on the guanidinoacetate methyltransferase (GAMT) deficiency condition nomination for possible inclusion on the RUSP. Following this report, the ACHDNC expects to vote on whether to recommend the Secretary add GAMT deficiency to the RUSP;
- 2) An update on the Krabbe disease condition nomination;
- 3) A possible vote on whether to move Krabbe disease forward to full evidence-based review;
- 4) A presentation on homocystinuria newborn screening status; and
- 5) A presentation on the Newborn Screening Family Education Program.

The agenda for this meeting includes a potential vote which may lead to a decision to recommend a nominated condition (GAMT deficiency) to the RUSP. In addition, as noted in the

agenda items, the Committee may hold a vote on whether or not to recommend a nominated condition (Krabbe disease) to full evidence-based review, which may lead to a recommendation to add or not add a condition/conditions to the RUSP at a future time.

Agenda items are subject to change as priorities dictate. Information about the ACHDNC, including a roster of members and past meeting summaries, is also available on the ACHDNC website listed above.

Members of the public will have the opportunity to provide comments. Public participants may request to provide general oral comments and may submit written statements in advance of the scheduled meeting. Oral comments will be honored in the order they are requested and may be limited as time allows. Subject to change: members of the public registered to submit oral public comments on GAMT deficiency are tentatively scheduled to provide their statements on Thursday, May 12, 2022. Members of the public registered to provide statements on all other newborn screening related topics are tentatively scheduled for Friday, May 13, 2022. Requests to provide a written statement or make oral comments to the ACHDNC must be submitted via the registration website by 12:00 PM ET on Friday, May 6, 2022.

Individuals who need special assistance or another reasonable accommodation should notify Alaina Harris at the address and phone number listed above at least 10 business days prior to the meeting.

**Maria G. Button,**

*Director, Executive Secretariat.*

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